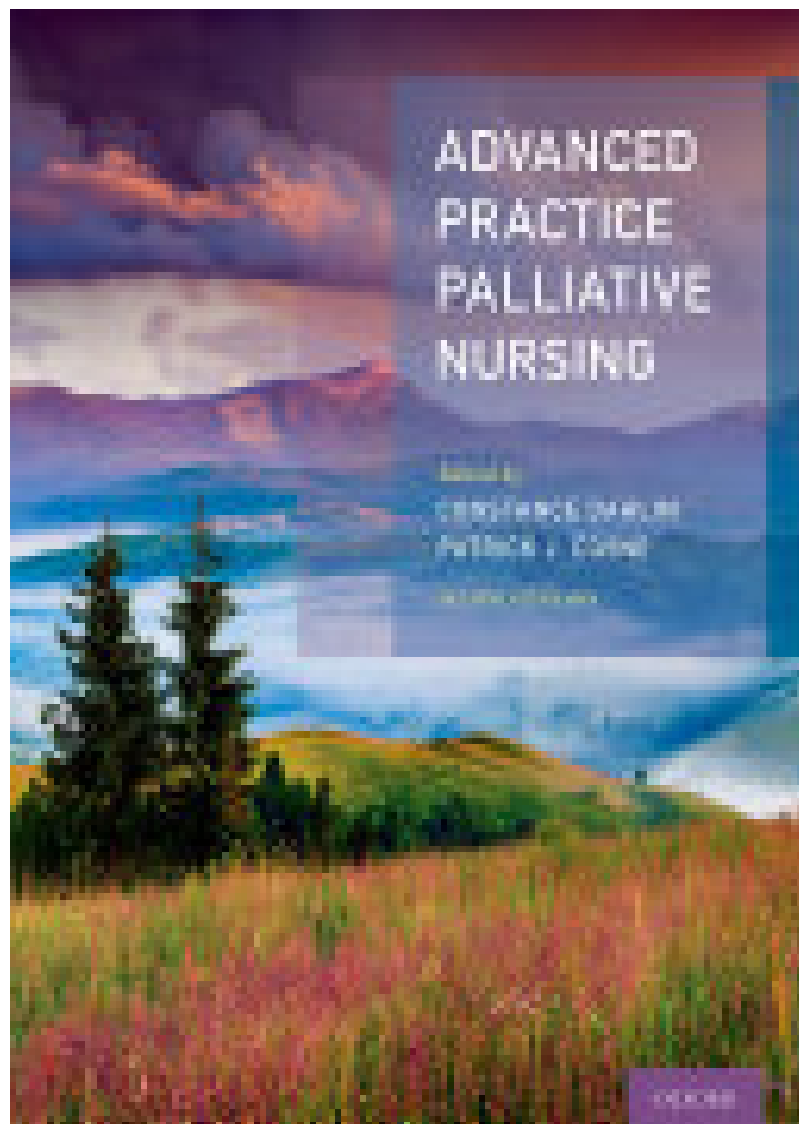


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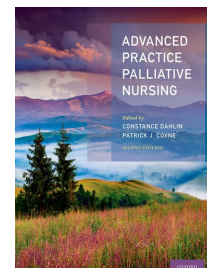


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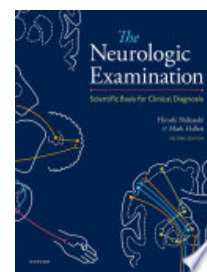
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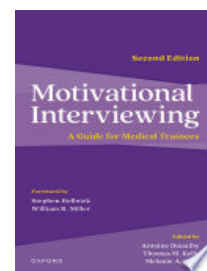
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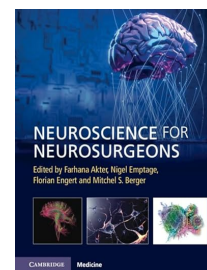
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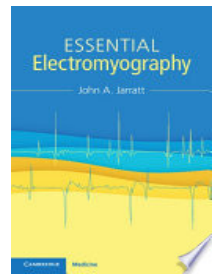
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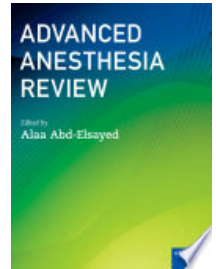
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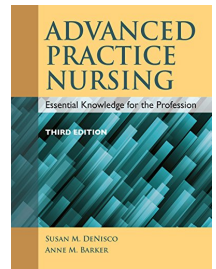
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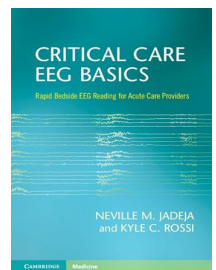
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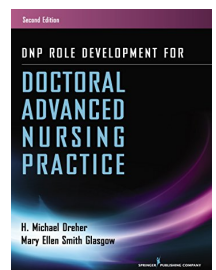
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PRACTICE PALLIATIVE NURSING

Edited by

CONSTANCE DAHLIN
PATRICK J. COYNE

SECOND EDITION

OXFORD

ADVANCED PRACTICE
PALLIATIVE NURSING

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We dedicate this second edition to all palliative APRNs who step in every day to promote access to quality care for individuals with serious illnesses and support family caregivers. You provide excellence in palliative care and promote palliative care equity and inclusion to diverse populations with unique needs. As palliative© APRNs, you create new programs and initiatives across clinical, educational, research, policy, and payment settings, forge new roles, develop new programs, conduct palliative research and quality improvement initiatives, create new technologies, and steer social justice within palliative care. We know it takes courage, knowledge, skills, strength, energy, and support to do this work.

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PREFACE

A palliative care textbook is always a labor of love. It symbolizes one's passion and commitment to the specialty. The ability to accomplish such a textbook is only through collaboration, patience, a sense of humor, and a north star of excellence and quality. The first edition of *Advanced Practice Palliative Nursing* was born out of the fact that there was no specific textbook for palliative APRNs. Prior to its publication, many seasoned APRNs learned content along the way and applied it to the APRN role. The goal of the first edition was to capture the uniqueness of the role, as well as validate and codify practice and ground the role the evidence, practice, and research. Each chapter was led by a practicing APRN to assure authenticity. Since that time, we have been thrilled from the outpouring of support for *Advanced Practice Palliative Nursing* as many APRNs said it met their need and their practice.

We recognize that we need to assure education and resources to the cadre of APRNs who will need to practice both primary and specialty palliative nursing. APRNs will need to develop new roles, lead new programs, and care for many populations across all health settings. The world and practice environment has changed considerably since the first edition. The APRN role continues to be the fastest growing segment of healthcare, and there will be a burgeoning of care for older adults. The current social construct puts more emphasis on the role of palliative care in crises including infectious disease such as the COVID-19 pandemic, humanitarian crises from conflicts, and natural disasters such as fires, floods, earthquakes, hurricanes, and the like. And the emphasis on health equity is urgent in palliative care, an issue brought to the forefront by the disparities illuminated by COVID-19 and structural racism.

Our plan had been to initiate the next edition in late 2022, as we were in the middle of other projects. However, the pandemic changed everyone's plans and it changed ours. We immediately thought to revise this edition, knowing that palliative APRNs were answering the call of the pandemic in many ways. They were particularly on the frontlines since palliative care expertise was needed to support patients in the crisis. We put out a call to authors and were pleasantly surprised when many said this would be a great diversion and provide some normalcy in a chaotic world. We were even more thrilled that 32 new chapter authors stepped in. To assure authenticity to each chapter, it was a requirement that the lead author of each chapter was an APRN currently in practice. Many of the authors APRNs are certified in advanced hospice and palliative nursing (ACHPN). It was a joy to coach and mentor them to succeed in the production of their chapters. We are grateful for all authors' contributions and appreciate the sharing of their expertise.

As a result, this textbook provides the essential knowledge and attitudes to improve skills and practice in palliative nursing to assure quality care. We hope it serves as a foundation for advanced practice palliative nursing practice. It is intended for the graduate nursing student as well as the novice, advanced beginner, and competent palliative APRN to support their specialty palliative care practice. It is also intended to support all APRNs in their provision of primary palliative care. We also hope it promotes role delineation and development within the spectrum of APRN practice. Finally, it is directed to nurse educators to help support their learners in primary and specialty palliative nursing and offer a curricular resource in preparing the next generation of palliative APRNs. We hope the reader will find the knowledge helpful to their practice and appreciate that it reflects current practice and research.

Constance Dahlin and Patrick J. Coyne

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We are grateful for the support and understanding of our families as we follow our passion to further the field. We thank Dr. Betty Ferrell for her previous editorship.

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SECTION I

THE PALLIATIVE APRN

PALLIATIVE APRN PRACTICE AND LEADERSHIP

PAST, PRESENT, AND FUTURE

Constance Dahlin and Patrick J. Coyne

KEY POINTS

- The foundational principles of nursing and palliative care are synergistic. Modern nursing has always focused on alleviating suffering for individuals in health and illness. Palliative care focuses on quality of life.
- All advanced practice registered nurses (APRNs) practice primary palliative care within their practice. Specialty palliative APRNs focus on more complex care for individuals with serious illness.
- Palliative APRNs promote access to palliative care, facilitate evidence-based palliative practices, and deliver safe, quality palliative care across settings and populations.
- Palliative APRN leaders are essential to the evolution of palliative care.

HISTORY OF NURSING AND PALLIATIVE APRNs

As the largest segment of healthcare providers, nurses have a prominent role in the front line of care. Nurses spend the most time with patients and families. This proximity allows for comprehensive assessment of the person and family to facilitate personalized care, implementation and evaluation of the treatment plan, and care coordination. Nurses are uniquely positioned in healthcare to observe family interactions, support a patient's coping, and listen to a patient's inner most thoughts and concerns across many situations. Advanced practice registered nurses (APRNs) are one of the fastest growing segments of nursing and healthcare and will continue to have a growing influence on the accessibility and quality of healthcare.^{1,2}

Both nursing and palliative care have evolved to focus on health, wellness, and caring across a continuum.³ Nurses protect, promote, and optimize human function; prevent illness and injury; and alleviate suffering through their compassionate presence, including individuals coping with actual or potential serious illness.⁴ Florence Nightingale and Mary Seacole established nursing practice while caring for soldiers in the Crimean War, many of whom were critically wounded.⁵ Thus, the essence of nursing was grounded in caring for gravely ill individuals. When nursing moved to the United States,

Clara Barton of the American Red Cross advanced nursing through the Civil War. Again, nursing practice was based in the care of soldiers wounded in battle.⁶

Nursing has developed in its breadth and scope of practice to include registered nurses (RNs) and graduate-level (master's or doctoral)–prepared specialty nurses. In the mid-twentieth century, four advanced practice nursing roles developed: certified nurse midwife, nurse practitioner (NP), clinical nurse specialist (CNS), and certified nurse anesthetist. These roles play a significant part in hospice and palliative care in the United States today. This textbook highlights how APRNs are leaders in the assurance of high-quality palliative care for all, the delivery of palliative care, the development and administration of palliative programs, advocacy in policy related to palliative care, access to palliative care education, and the development and participation in necessary palliative care research, with an emphasis on nursing.

HISTORY OF HOSPICE AND PALLIATIVE CARE

The modern hospice movement was established in the 1960s in England by Dame Cicely Saunders, a physician who was first a nurse, then a social worker. At St. Joseph's Hospice, Dr. Saunders followed her calling to promote compassionate care to the dying, calling on her background in nursing and social work. She then founded St. Christopher's Hospice to further develop hospice care.⁶ These concepts traveled to the United States through the work of Dr. Florence Wald, then dean of the Yale School of Nursing. Dr. Wald developed an expansive nursing curriculum that emphasized the nursing skills necessary for caring for dying patients, specifically pain and symptom management and communication.⁷ Dr. Wald stated, "Hospice care is the epitome of good nursing care." She asserted, "It enables the patient to get through the end-of-life on their own terms. It is a holistic approach, looking at the patient as an individual, a human being. The spiritual role nurses play in the end-of-life process is essential to both patients and families."⁷ Dr. Wald then founded the Connecticut Hospice, the first hospice in the United States.

In 1982, the Medicare Hospice Benefit was enacted, offering benefits to patients with a terminal illness. Specific *Medicare Hospice Conditions of Participation* (CoPs) directed hospices to offer a certain set of services to patients and families.⁸ Within the benefit, nursing has a prominent

role as a core service. In programs across the United States, the majority of hospice care is provided by nurses visiting patients' homes. However, in its infancy, the Medicare Hospice Benefit recognized only RN practice. It was not until recently that the Medicare Hospice Benefit even acknowledged that APRNs lead hospice teams and oversee the care of hospice patients. The most recent version of the CoPs (2011) clarifies the role of the APRN.⁹

In addition, when the Medicare Hospice Benefit was started, care of dying patients was marked by a lack of consistency in care provision and little consensus on the defining characteristics of palliative care or quality indicators for adults and children. Even less was known about patients with serious illness. Research from the 1990s confirmed the worst fears about healthcare. *The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment* (SUPPORT) demonstrated a failure to honor patients' preferences even when patients were clear about their wishes and preferences.¹⁰ The study found a continued lack of communication between patients and their healthcare providers about end-of-life care. Furthermore, patients who were seriously ill and dying reported high levels of pain and other symptoms, extensive financial stress, and, most importantly, a lack of concordance between care provided and their care preferences. Despite patient preferences to focus on quality of life, aggressive care was often continued despite reduced quality of life.¹⁰ In the intervention arm of the study, nurse-conducted patient interviews did not improve outcomes in aligning care with patient goals. However, there was variation in the SUPPORT study: both APRNs and RNs were used in the intervention which meant variability in communication skills and scope of practice. This may have caused an inconsistency in the interventions for patients and, ultimately, the affected consistency of outcomes.

As the findings from SUPPORT were being disseminated in the mid-1990s, hospice concepts moved into the academic hospital setting in the form of palliative care.¹¹ This care applied hospice concepts of symptom management, family support, goal-centered care, and quality of life earlier in the care of hospitalized patients. Care first focused on adults with serious and life-threatening illnesses whose care was complicated, as well as on terminally ill patients who were not ready for hospice.¹¹ Specialty pediatric palliative care then developed as well.

INCEPTION OF PALLIATIVE CARE AND PALLIATIVE NURSING

Pioneer palliative care programs were developed across the country. Many of these palliative care services had a large presence of APRNs.¹¹ With their enhanced graduate education and scope of practice, APRNs offered a wide range of clinical services to patients and families, such as taking histories, performing physical examinations, developing diagnoses, creating care plans, prescribing medications, and offering treatment options.^{11,12} Moreover, many APRNs had been selected as faculty scholars of the Open Society *Project on Death in America* to improve care at the end of life.¹³ APRNs

also had prominent roles in program development, research, and education of patients, families, professional colleagues, and health systems. The challenge was ensuring appropriate education and training so that APRNs could move into these roles. The development of the specialty of palliative APRN practice was just beginning. See Box 1.1 for a review of the specialty.

In the early years, most APRNs who moved into palliative care roles had to design their own education and support for clinical decision-making since there were no organized educational plans. Frequently, APRNs learned aspects of a palliative approach through clinical care over months to years. It was often the case of on-the-job skill building while developing individual models of care. Often education, practice expertise, and skills emanated from either oncology nursing or AIDS/HIV nursing, which involved a range of skills associated with symptom control, care at end of life, coping, and bereavement. Other nurses moved from hospice care into palliative care because of shared experience in pain and symptom management, counseling about life-limiting illness, and working with an interprofessional team.

ESSENTIAL REPORTS

The release of essential reports about dying in America influenced palliative advanced practice nursing. The 1997 Institute of Medicine (IOM) report *Approaching Death* described the state of end-of-life care in America.¹⁶ This report recommended the subspecialty of palliative care, reviewed the use of medications for pain and symptom management, supported financial investment in palliative care, and appealed for professional education that included palliative care content in various curricula, textbooks, and training programs.¹⁴

EVOLUTION OF PALLIATIVE CARE

The Precepts of Palliative Care were released by Last Acts (formerly a Robert Wood Johnson Foundation-funded organization, which was enveloped within the National Hospice and Palliative Care Organization).¹⁵ These precepts reaffirmed the comprehensive approach of palliative care as a specialized area of expertise. *The Precepts of Palliative Care* also stated that care should respect patient choices, affirmed that care utilizes the strengths of the interdisciplinary team, and encouraged the building of palliative care support through financing, outcomes, and research.¹⁵

In 2002, Last Acts published a seminal document, a state-by-state report card of end-of-life care in America, which captured a fairly bleak picture of palliative care in the United States.¹⁶ It promoted much discussion about a unified response from the palliative care community. This state reporting was subsequently monitored by the Center to Advance Palliative Care. Other significant reports included two IOM reports, *When Children Die* and *Crossing the Quality Chasm*, and a monograph by the National Hospice Work Group and the Hastings Center in association with the National Hospice and Palliative Care Organization (NHPCO) entitled *Access to Hospice Care: Expanding Boundaries, Overcoming Barriers*.¹⁷⁻¹⁹

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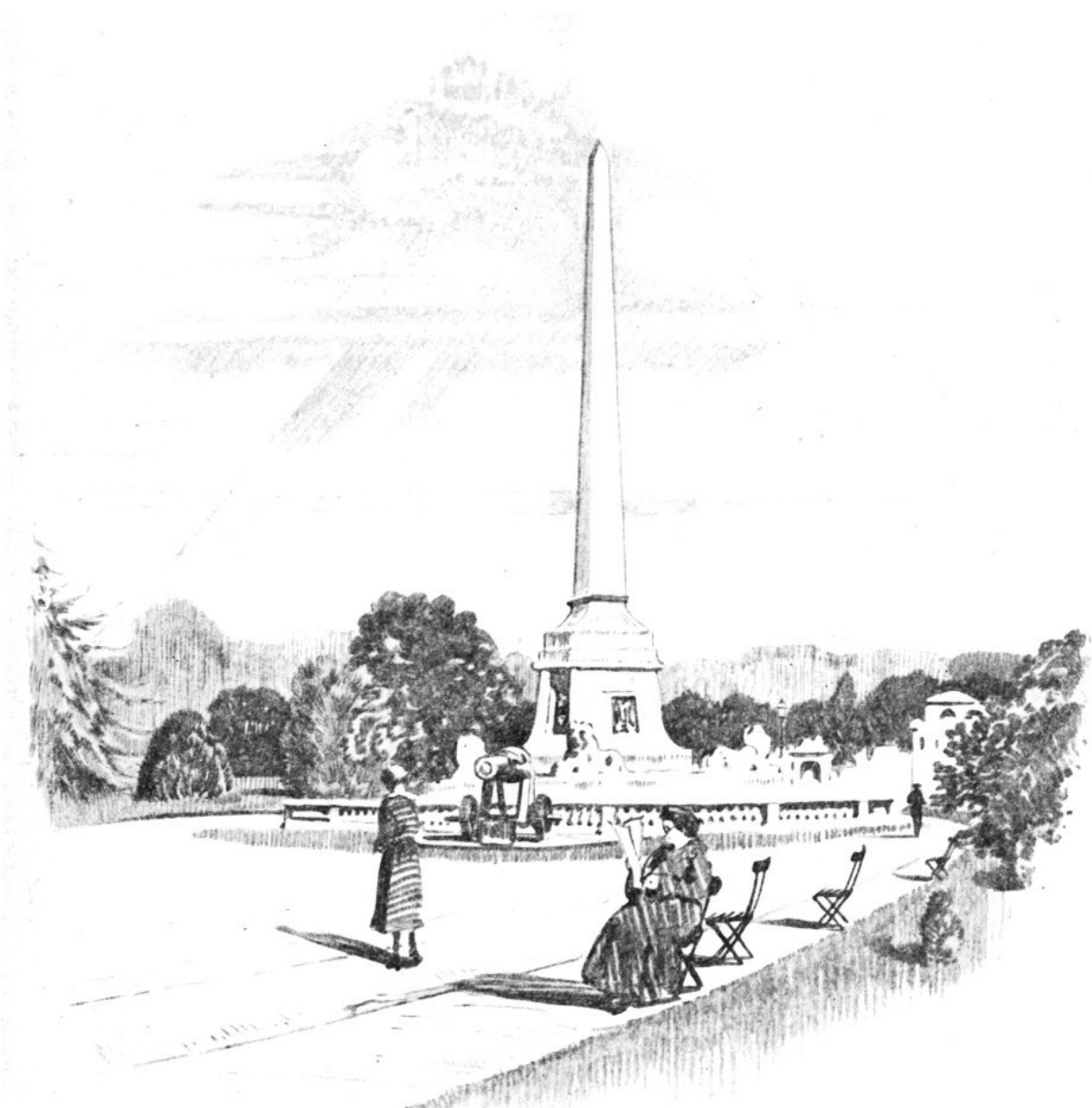
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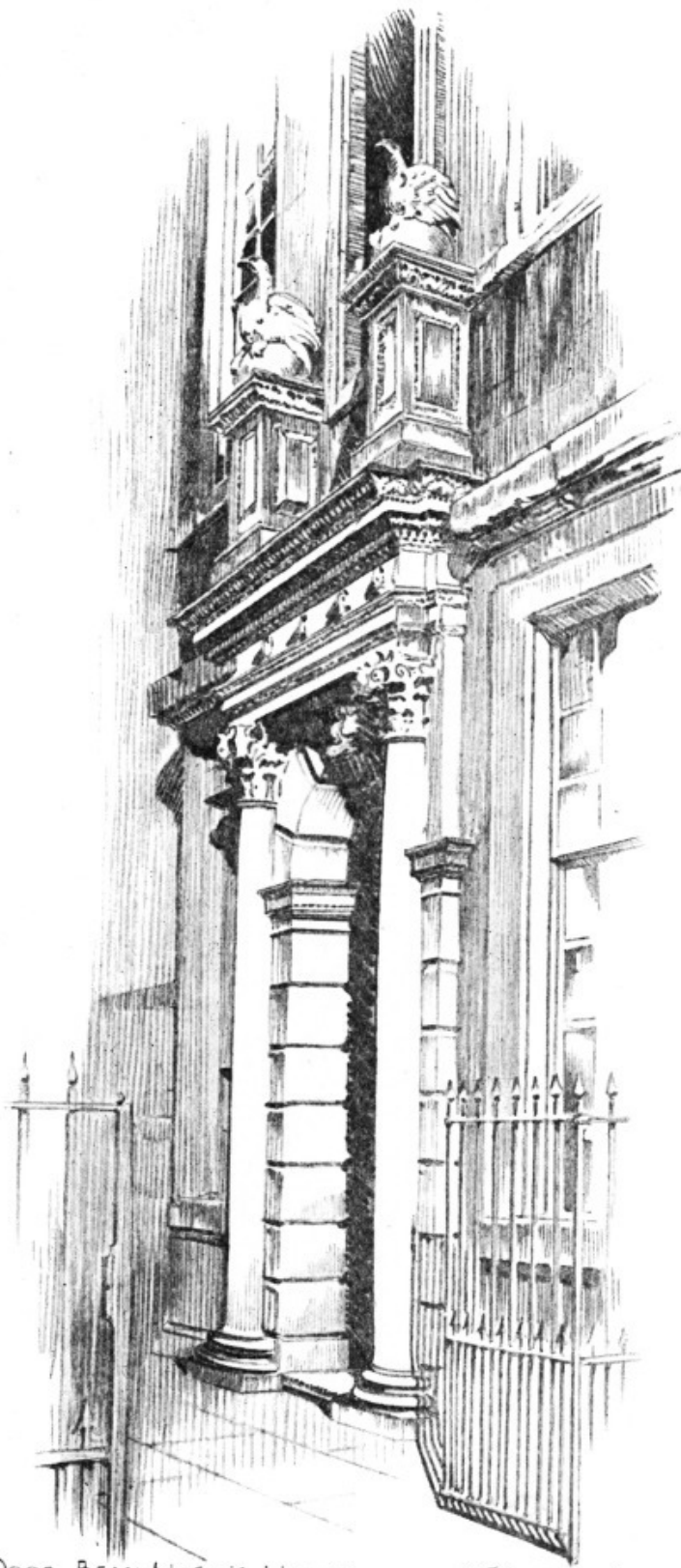
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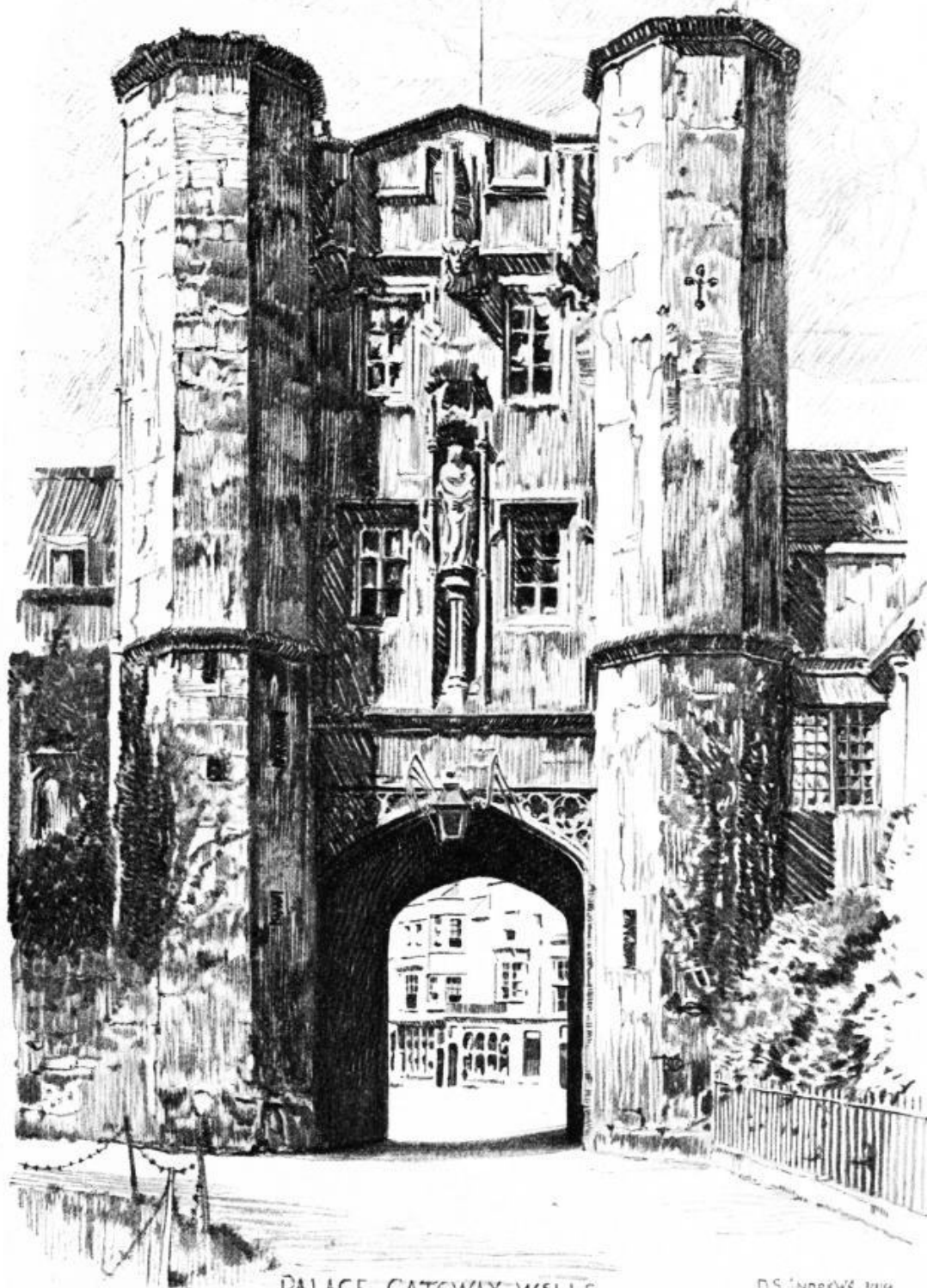
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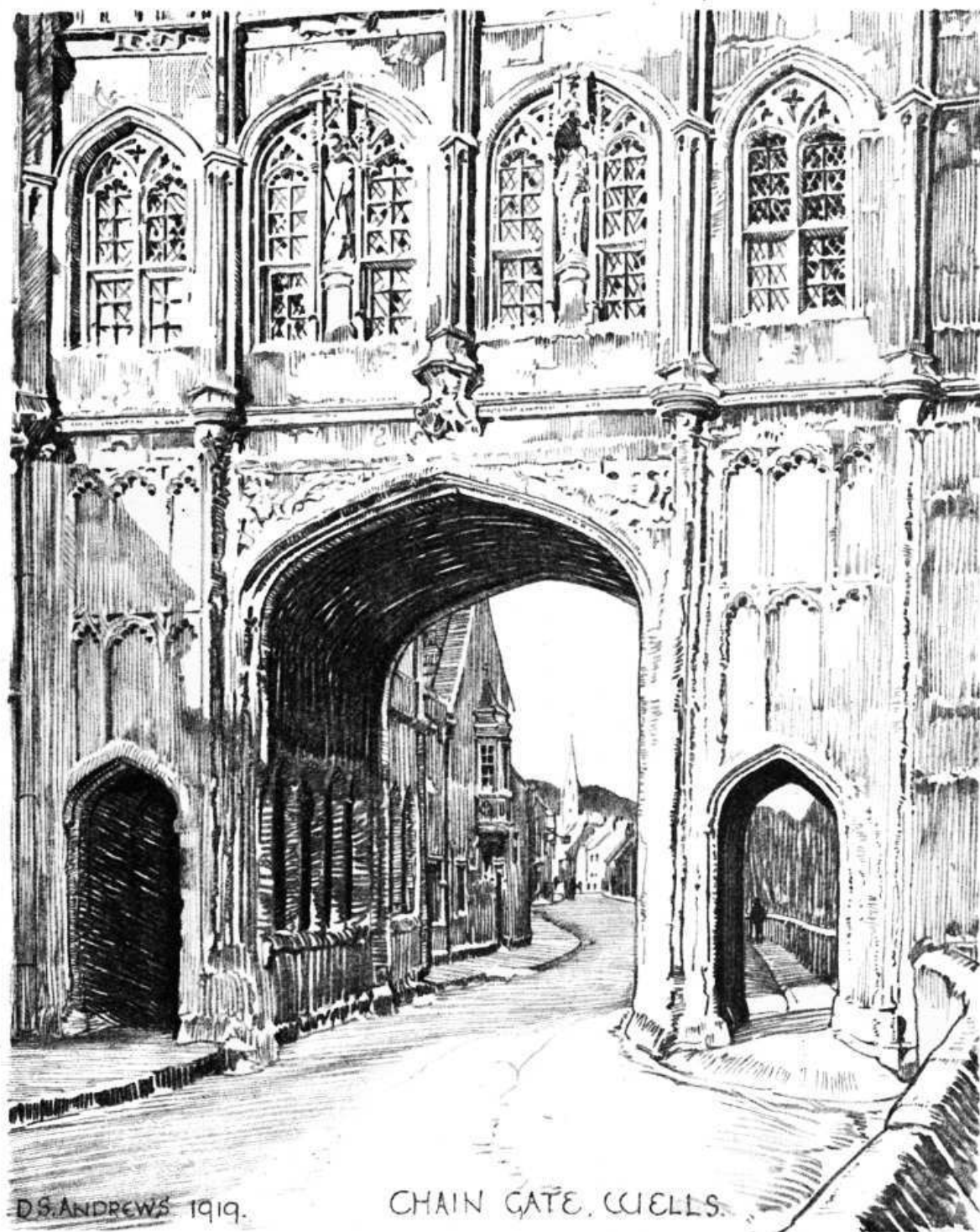
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